

HB 5128 A ACT CONCERNING FUNDS : Keep DDS funds within DDS

This letter is in support of keeping within DDS the funds already appropriated by the Legislature to provide services for Connecticut's population who have intellectual/developmental disabilities.

I'm a single mom, a Senior Citizen now, 65, and expected that my 4 severely disabled adult sons whom I adopted would have DDS residential placements by now. Three of them do, living in community residences and attending day programs funded by DDS. But my 4th son, Patrick, most disabled of all, was left on the DDS residential wait list, Priority 1. And he's still waiting.

Patrick, 34, is a charming young man with a ready smile, outgoing, sociable and with a great sense of humor. He is also not only intellectually disabled, but quadriplegic, blind, epileptic, and medically fragile. He has a G-tube, J-tube, and a Central IV port. He chronically aspirates, resulting in pneumonia, even Life-Star flown twice. Patrick has a trach (artificial airway) which must be suctioned to clear secretions and monitored for blockage, so he requires round-the-clock nursing. He is also on oxygen now.

Patrick had only 40-50 hours a week of nursing, and I did the remaining hours, the equivalent of 3 full-time jobs, sleeping only 2-4 hours a night.

When I was diagnosed with the beginnings of macular degeneration and cataracts, I again asked for a DDS placement before my vision becomes blurry. "Not until you go blind," I was told by his DDS worker at the time, because there were no available funds for him.

In October the bottom fell out. Patrick lost his only full-time nurse, with no available replacement. I was now doing 150 hours a week of care, almost 4 full-time jobs. Without his nurse, he was also no longer able to attend the day program which he loved.

Incredibly, DDS met to review Patrick's case based on these new circumstances but he was not reclassified from P1 to Emergency. Was that because there was no available residential funding? DDS did say that Patrick could take over a vacant DDS bed in an ICF group home with round-the-clock nursing because funding stays with the bed when it is vacated. So they did recognize his urgent need! But because of ongoing cuts to DDS, there wasn't even one vacancy in the whole state of the kind Patrick needs ...an ICF home with round-the-clock nursing like his younger brother lives in. And private providers don't have the needed DDS funds to create new ones! Patrick would have to wait until a vacancy opened up by someone dying, and even then he could be competing with others for that one vacancy.

In November, Patrick was accepted into the Hospital for Special Care, Respiratory Step Down Unit. Yes, DDS said he was not an emergency yet he was accepted into a hospital step down unit. It was a sudden move with only 1 1/2 days notice, and no time for transitioning him. Neither of us even had time to take a tour in advance of his placement. What a cruel, frightening way to disrupt his life, compounded immensely by his inability to see. Patrick was placed in a 4-bed hospital room crowded with hospital beds, medical equipment and other patients unable to verbally interact with him. One is in a coma, one sleeps almost all the time, and another of his room mates, a grandfather, has already passed on. Since Patrick is blind, he completely depends upon verbal interactions for stimulation. Patrick is starved for social interactions and activities and also deeply misses the opportunity to go out to a day program.

This is only an INTERIM placement, however, and Patrick is still on the DDS residential wait list. After living a rich family life, fully included in public school, participating in Scouts and soccer with his peers, Patrick should not be warehoused in a hospital where his joy of living diminishes each day. He should be living in a residential home with friends, activities, and

loving staff who are like family and have time to interact with him. He should have the opportunity to go out to a day program again, too.

This is not the adult life I dreamed of for Patrick. I'm sure you wouldn't want this for a member of your family, either.

I wish Legislators and the Governor would visit some of the families on the wait list who have sons or daughters with DDS LON scores of 7 (like Patrick has) to see firsthand how they struggle to get through each day, knowing there are endless days and years still ahead. I would also welcome them to contact me to visit Patrick and see the inappropriateness of his interim placement in meeting his overall needs.

By keeping DDS funds within the system, the residential wait list could be reduced simply by using money **ALREADY APPROPRIATED** by the Legislature for DDS usage. Please use both fiscal sense and compassion in deciding the fate of this bill - and the fate of all the families it could help. With over 2,000 on the growing DDS residential wait list, and new wait lists for other DDS services, there are families in all districts, including yours, whose futures are dependent upon the passage of this bill.

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